Advance directives from a cross-cultural perspective

Biller-Andorno, N ; Brauer, S

DOI: https://doi.org/10.1111/j.1467-8519.2009.01786.x

bioethics

Bioethics ISSN 0269-9702 (print); 1467-8519 (online)
Volume 24 Number 3 2010 pp ii–iv

doi:10.1111/j.1467-8519.2009.01786.x

EDITORIAL

ADVANCE DIRECTIVES FROM A CROSS-CULTURAL PERSPECTIVE

Advance directives may appear a theme of the past. Terms such as 'surrogate decision-making', 'durable power of attorney', 'living wills' or 'right to die' come to mind – terms that were central to debates that took place decades ago, when the cases of Nancy Cruzan and Karen Quinlan caught the attention of courts as well as the wider public.

Still, advance directives are not a settled issue, for several reasons. For one, only a limited number of (mostly Western) countries have had a sustained discussion that has led to an explicit normative frame. Other countries are currently in the process of drafting legislation or have just finished doing so (such as Switzerland) whereas, in many countries around the globe, these developments are still projects for the future.

But even in the countries where well-defined legal and ethical frameworks have been established, important questions remain regarding their clinical implementation. Changes in the terminology, such as the tendency to use 'advance care planning' rather than 'advance directives' illustrate a shift in focus from patients trying to secure their influence on future clinical decisions while still competent to a model that emphasizes shared decision-making, which includes possible future scenarios.

A third reason that warrants continued attention to the ethical and legal issue of advance directives is the fact that the normative frames that countries have developed or are in the process of developing, differ significantly, in particular with regard to the scope and legal status of advance directives. This raises cross-border issues that are interesting from a legal point of view – such as the portability of advance directives – but also draws attention to underlying cross-cultural questions: Do we have a minimal consensus on what the role of advance directives should be in our different health care systems and societies? Is there a common understanding of why we think advance directives should be offered in the first place? Do we agree we want to strengthen patient autonomy, and what does this mean for family involvement in clinical decisions? Can advance directives accommodate different ideas about what clinical decision-making should look like – in terms of whom to involve, how to communicate and which factors to take into consideration, with what weight?

From a global perspective, advance directives remain an interesting and highly topical focal point for bioethical questions, extending beyond the patient-physician-relationship to broader issues, such as individualistic vs. relational understandings of autonomy. The Institute of Biomedical Ethics of the University of Zurich, Switzerland, sought to contribute to an international exchange bringing together countries which have dealt with the issues for almost half a century, such as the USA, and others that are just starting to confront them, such as some Eastern European countries. It organized two events that provided opportunities for such an exchange to happen: the Exploratory Workshop 'Advance Health Care Directives: Towards a Coordinated European Approach' that took place in Zurich from June 19–21, 2008 within the Research Networking Programme of the European Science Foundation and a special session on 'Advance directives from a cross-cultural perspective' that was organized for the 9th World Congress of Bioethics in Croatia in the same year. The call for papers, to which some workshop participants resp. session speakers chose to react, yielded responses from the US, Australia, several Eastern and Western European countries, Turkey, Israel, and Korea.

The selected papers follow different strands of inquiry, some exploring distinct cultural contexts and the role advance directives play in them, others drawing on their own cultural background to address what they perceive as shortcomings of advance directives as they have been traditionally conceived, and still others focusing on the challenges of international policy and its normative justification.

The latter issue is taken up by Violeta Besirevic in *End-of-Life Care in XXI Century: Advance Directives in Universal Rights Discourse*. The author explores international laws and declarations, such as the UNESCO Declaration of Bioethics and Human Rights and the Oviedo Convention, which deal with advance directives, or at least with the idea of accounting for the previously expressed wishes of currently incompetent patients. Questioning whether the normative basis underpinning these regulations – such as the principles of autonomy, dignity and informed consent – are truly universal, she concludes that in clinical practice, this is far from the case. She favors the idea that advance directives should be only one option among others to manage incompetent patients but envisions a universal legally binding convention that would put all countries under an obligation not to violate the ethical right to autonomy.

In 'A Korean Perspective on Developing a Global Policy for Advance Directives', Myongsei Sohn, Soyoon Kim, Ki-Hyun Hahm, Hyoung Wook Park and Hyun Hee Kang also call for a global policy that would settle cross-border issues as they arise in the context of medical tourism. At the same time, it would strengthen the role of advance directives in countries in which they are still widely unknown or considered irrelevant or

inappropriate and help improve existing national policy in others. Sohn and his co-authors emphasize the respect for patient autonomy as a universal normative basis for advance directives – even if patients' choices appear 'unreasonable or foolish, even if their choice conflicts with the wishes of others'. Sohn is fully aware of the obstacles – be they a matter of cultural reservations or of different priorities in resource-poor health care systems – that such an initiative would encounter. Yet he remains convinced that an intergovernmental agency such as the World Health Organization should explore the projected benefits and challenges of a global policy on advance directives.

The point that advance directives may be controversial not only from an international perspective but even within a relatively homogeneous society is illustrated by the contribution of Mathijs van Wijmen, Mette Rurup, Roeline Pasman, Pam Kaspers and Bregje Onwuteaka-Philipsen. As their paper 'Advance Directives in the Netherlands: An Empirical Contribution to the Exploration of a Cross-Cultural Perspective on Advance Directives' shows, the likelihood of having an advance directive or of wanting to draw up one in the future correlates positively with level of education and negatively with having a religious belief (Catholic or Protestant). Interestingly, only 7% of the Dutch general population currently have an advance directive, whereas 13% do not intend to formulate one in the future, the rest being in principle open to the idea or definitively wanting to have one later on. Comparing the Dutch data to empirical studies from other countries, the authors conclude that any move towards global policy can at this point only consist of more in-depth studies aimed to improve understanding of the differences within and between cultural settings.

Whereas the Dutch context may be characterized by pluralism, liberalism, a prominent societal debate on euthanasia and a broad consensus on autonomy as a fundamental principle, the next contribution focuses on a rather different cultural context. In *Advance Directives in Turkey's Cultural Context: Examining the Potential Benefits for the Implementation of Patient Rights*, Tolga Guven and Gurkan Sert present the Turkish healthcare system as being in a transition from paternalistic practices towards a more patient rights centered approach. While hinting at the need for culturally adapting the concept of autonomy in the light of patients' understanding of the term and the significant involvement of the family in medical decisions in Turkey, the authors cite empirical data that show the discontent of patients with paternalistic practices that exclude them from information and decision-making processes.

Carmel Shalev in 'Reclaiming the Patient's Voice and Spirit in Dying: An Insight from Israel' offers a critique of how dying has become a material rather than a spiritual process in modern hospitals. Advance care planning, for her, is a valuable instrument for helping the patient overcome a clinical context that is framed as a battle against death. Developing a relational understanding of autonomy the author aims to create a space for dying patients in which they can address what matters to them together with those who are close to them. Like the previous contributor, Shalev emphasizes the potential of advance directives for fostering communication and patient empowerment, in an environment in which empathy and responsiveness to patients' genuine needs may not be developed to their full potential.

The final contribution by Assya Pascalev and Takis Vidalis returns to the issue of international policy. In 'Vague Oviedo': Autonomy, Culture and the Case of Previously Competent Patients' the authors use the European Convention on Human Rights and Biomedicine, also known as the Oviedo Convention, to demonstrate the challenges of international policy on advance directive. They show the vagueness implied in several formulations of Article 9, such as the patient's previously expressed wishes needing 'to be taken into account', and distinguish two groups of European countries that differ both in the institutionalization of advance directives and in the restrictions they impose on the involvement of third parties such as physicians and family members. Pascalev and Vidalis follow the two previous contributors in suggesting a relational understanding of autonomy that takes the social and cultural embeddedness of individuals into account. Autonomy understood as a culturally sensitive concept that leaves room for local cultural norms, they argue, can serve as a normative basis for a universal moral obligation to respect the prior wishes of the patient, at least in a minimal way.

It is quite fascinating to see how bioethical issues that would hardly raise an eyebrow in settings that seem to have discussed them to the point of saturation appear in a new light when considered from a cross-cultural perspective. Cross-cultural differences may be found not only at the global level but also between social, religious, ethnic or otherwise defined groups in the same country. Addressing issues arising from such cross-cultural perspectives is at the same time intellectually appealing and practically relevant.

Advance directives remain a challenge not only with regard to their clinical implementation in very different contexts but also from a theoretical point of view, probing the level of normative justification, as well as from a policy perspective that needs to define an appropriate space for cultural interpretation and adaption.

At the same time, advance directives are an excellent test case for a meaningful cross-cultural exchange on the more general question of 'Who has a say in whose decisions, and why?'. Having an opportunity to discuss and

negotiate these fundamental issues from an international or even a global perspective can greatly advance the understanding of the social fabric of our societies.

As editors of this special issue we would like to thank the European Science Foundation and the University Research Priority Program of the University of Zurich for generous support of our activities. We would like to thank all participants in the ESF-Workshop as well as the IAB Special Session for their precious input. Thanks also to all reviewers who have helped the authors and us with their thoughtful and constructive commentaries. Last but not least we wish to thank the editors of Bioethics, Ruth Chadwick and Udo Schüklenk, for their interest in the topic, and Clancy Pegg for coaching us so diligently through the whole process.

NIKOLA BILLER-ANDORNO AND
SUSANNE BRAUER